

General

Title

Epilepsy: percentage of all patients with a diagnosis of epilepsy, or their caregivers, who were provided with personalized safety issue and epilepsy education at least once annually.

Source(s)

American Academy of Neurology. Epilepsy update: quality measurement set. St. Paul (MN): American Academy of Neurology (AAN); 2014. 83 p.

Measure Domain

Primary Measure Domain

Clinical Quality Measures: Process

Secondary Measure Domain

Does not apply to this measure

Brief Abstract

Description

This measure is used to assess the percentage of all patients with a diagnosis of epilepsy, or their caregivers, who were provided with personalized safety issue and epilepsy education at least once annually.

Rationale

People with epilepsy are at a greater risk for injury and accidents (England et al., 2012; Kobau et al., 2008). Providing patients or caregivers with personalized epilepsy safety issue information and education will increase personal safety while promoting self-management and improving quality of life.

The following clinical recommendation statements are quoted verbatim from the referenced clinical guidelines and represent the evidence base for the measure:

At the time of initial seizure evaluation, the patient should receive information on driving

restrictions, safety and injury prevention (Pugh et al., 2007).

Patients with epilepsy should receive an annual review of information including topics such as: chronic effects of epilepsy and its treatment including drug side-effects, drug-drug interactions, effect on bone health; contraception, family planning, and how pregnancy and menopause may affect seizures; screening for mood disorders; triggers and lifestyle issues that may affect seizures; impact of epilepsy on other chronic and acute diseases; driving and safety issues (Pugh et al., 2007).

Adults should receive appropriate information and education about all aspects of epilepsy. This may be best achieved and maintained through structured self-management plans (National Institute for Health and Clinical Excellence [NICE], 2012).

Healthcare professionals should adopt a consulting style that enables the child, young person or adult with epilepsy, and their family and/or carers as appropriate, to participate as partners in all decisions about their healthcare, and take fully into account their race, culture, and any specific needs (NICE, 2012). Children, young people and adults with epilepsy and their families and/or carers should be given, and have access to sources of, information about (where appropriate): epilepsy in general; diagnosis and treatment options; medication and side effects; seizure type(s), triggers, and seizure control; management and self-care; risk management; first aid, safety and injury prevention at home and at school or work; psychological issues; social security benefits and social services; insurance issues; education and healthcare at school; employment and independent living for adults; importance of disclosing epilepsy at work, if relevant (if further information or clarification is needed, voluntary organizations should be contacted.); road safety and driving; prognosis; sudden death in epilepsy (SUDEP); status epilepticus; life style, leisure and social issues (including recreational drugs, alcohol, sexual activity, and sleep deprivation); family planning and pregnancy; voluntary organizations, such as support groups and charitable organizations, and how to contact them. The time at which this information should be given will depend on the certainty of the diagnosis and the need for confirmatory investigations (NICE, 2012).

If children, young people and adults and families and/or carers have not already found high-quality information from voluntary organizations and other sources, healthcare professionals should inform them of different sources (NICE, 2012).

Adequate time should be set aside in the consultation to provide information, which should be revisited on subsequent consultations (NICE, 2012).

Checklists should be used to remind children, young people and adults, and healthcare professionals, about information that should be discussed during consultations (NICE, 2012).

Everyone providing care or treatment for children, young people and adults with epilepsy should be able to provide essential information (NICE, 2012).

The child, young person or adult with epilepsy and their family and/or carers as appropriate should know how to contact a named individual when information is needed. This named individual should be a member of the healthcare team and be responsible for ensuring that the information needs of the child, young person or adult and/or their family and/or carers are met (NICE, 2012).

The possibility of having seizures should be discussed, and information on epilepsy should be provided before seizures occur, for children, young people and adults at high risk of developing seizures (such as after severe brain injury), with a learning disability, or who have a strong family history of epilepsy (NICE, 2012).

Children, young people and adults with epilepsy should be given appropriate information before they make important decisions (for example, regarding pregnancy or employment) (NICE, 2012).

Information on SUDEP should be included in literature on epilepsy to show why preventing seizures is important. Tailored information on the person's relative risk of SUDEP should be part of the counselling checklist for children, young people and adults with epilepsy and their families and/or carers (NICE, 2012).

Adults with well-controlled epilepsy may have specific medical or lifestyle issues (for example, pregnancy or drug cessation) that may need the advice of a specialist (NICE, 2012).

At the (annual) review, children, young people and adults should have access to: written and visual information; counselling services; information about voluntary organizations; epilepsy specialist nurses; timely and appropriate investigations; referral to tertiary services including surgery, where appropriate (NICE, 2012).

Opportunity for Improvement

Research has demonstrated that people with epilepsy do not have a solid understanding of basic information about epilepsy, including knowledge about their diagnosis, seizure precipitants or triggers, specific seizure types(s), the purpose and potential side effects of seizure medications, safety concerns, and the risks of seizures (England et al., 2012; Long et al., 2000; Fraser et al., 2011; Sare et al., 2007; Tatum, Worley, & Selenica, 2012; Wicks & Fountain, 2012). Children and adolescents with epilepsy need increasing tailored knowledge about their condition over time (England et al., 2012). People with epilepsy, their families, and caregivers want more information than they currently receive (England et al., 2012; American Medical Association [AMA], 2014). Information and education should be provided in the best manner to meet their specific situations as patients maybe too ashamed or intimidated to request this information (England et al., 2012; AMA, 2014).

Evidence for Rationale

American Academy of Neurology. Epilepsy update: quality measurement set. St. Paul (MN): American Academy of Neurology (AAN); 2014. 83 p.

American Medical Association (AMA). Health literacy program. [internet]. Chicago (IL): American Medical Association (AMA); 2014 [accessed 2014 Feb 20].

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Kobau R, Zahran H, Thurman DJ, Zack MM, Henry TR, Schachter SC, Price PH, Centers for Disease Control and Prevention (CDC). Epilepsy surveillance among adults--19 States, Behavioral Risk Factor Surveillance System, 2005. *Morb Mortal Wkly Rep Surveill Summ.* 2008 Aug 8;57(6):1-20. [PubMed](#)

Long L, Reeves AL, Moore JL, Roach J, Pickering CT. An assessment of epilepsy patients' knowledge of their disorder. *Epilepsia.* 2000 Jun;41(6):727-31. [PubMed](#)

National Institute for Health and Clinical Excellence (NICE). The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care. London (UK): National Institute for Health and Clinical Excellence (NICE); 2012 Jan. 117 p. (Clinical guideline; no. 137).

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Sare G, Rawnsley M, Stoneman A, Duncan S. Men with epilepsy--the lost tribe? Results of a nationwide survey of men with epilepsy living in the UK. *Seizure.* 2007 Jul;16(5):384-96. [PubMed](#)

Tatum WO, Worley AV, Selenica ML. Disobedience and driving in patients with epilepsy. *Epilepsy Behav.* 2012 Jan;23(1):30-5. [PubMed](#)

Wicks P, Fountain NB. Patient assessment of physician performance of epilepsy quality-of-care measures. *Neurol Clin Pract.* 2012 Dec;2(4):335-42. [PubMed](#)

Primary Health Components

Epilepsy; personalized safety issues and education

Denominator Description

All patients with a diagnosis of epilepsy (see the related "Denominator Inclusions/Exclusions" field)

Numerator Description

Patients or their caregivers were provided personalized epilepsy safety issue and education and resources at least once a year (see the related "Numerator Inclusions/Exclusions" field)

Evidence Supporting the Measure

Type of Evidence Supporting the Criterion of Quality for the Measure

A clinical practice guideline or other peer-reviewed synthesis of the clinical research evidence

A formal consensus procedure, involving experts in relevant clinical, methodological, public health and organizational sciences

One or more research studies published in a National Library of Medicine (NLM) indexed, peer-reviewed journal

Additional Information Supporting Need for the Measure

Importance of Topic

Epilepsy data is lacking. In 2012, the Institute of Medicine released *Epilepsy across the Spectrum: Promoting Health and Understanding*, detailing epilepsy research disparities and highlighting specific areas where further research is needed, including the extent of epilepsy, consequences, comorbid conditions and outcomes of epilepsy (England et al., 2012). The following statistics only touch on the magnitude of epilepsy given lack of research and stigma:

It is estimated 2.2 million people in the United States are diagnosed with epilepsy, and 150,000 new cases of epilepsy are diagnosed in the United States annually (England et al., 2012).

Epilepsy prevalence might be underestimated because of underreporting associated with repercussions and stigma in disclosing epilepsy (Kobau et al., 2012).

Common comorbidities among people with epilepsy include somatic (i.e., fractures, asthma, diabetes, and heart disease), neurological (i.e., stroke, Alzheimer's disease, autism spectrum disorders, chronic pain), and mental health conditions (i.e., mood disorders, attention deficit hyperactivity disorders, anxiety disorders, suicidality) (England et al., 2012; Kobau et al., 2008).

It is estimated the number of people with epilepsy who die of sudden unexpected death in epilepsy (SUDEP) range from 1 of every 10,000 who are newly diagnosed to 9 of every 1,000 candidates for epilepsy surgery (England et al., 2012).

People with epilepsy are more likely to be unemployed or unable to work, have low annual household incomes, be obese and physically inactive, and to smoke (England et al., 2012; Kobau et al., 2008).

People with epilepsy have poorer overall health status, impaired intellectual and physical functioning, a greater risk for accidents and injuries, and negative side effects from seizure medications (Fountain et al., 2011; England et al., 2012; Kobau et al., 2008).

It is estimated the annual direct medical cost of epilepsy in the United States is \$9.6 billion. This

estimate does not include community service costs or indirect costs from losses in quality of life and productivity (England et al., 2012).

Opportunities for Improvement

Additional data on opportunities for improvement and gaps in care specific to the epilepsy measures can be located in the updated epilepsy measures.

A review of 261 patient responses using the PatientsLikeMe survey system indicated a gap remains between recommended care detailed in the 2009 epilepsy measurement set and the care delivered to patients with epilepsy (Wicks & Fountain, 2012).

The Institute of Medicine noted several gaps in care and opportunities for improvement, including 1) timely referrals and access to treatments, 2) epilepsy care and prevention, 3) education of persons with epilepsy and their families, and 4) the stigma of epilepsy (England et al., 2012).

Surgery continues to be heavily underutilized as a treatment for epilepsy, with significant disparities by race and insurance coverage (Englot et al., 2012).

Evidence for Additional Information Supporting Need for the Measure

American Academy of Neurology. Epilepsy update: quality measurement set. St. Paul (MN): American Academy of Neurology (AAN); 2014. 83 p.

England MJ, Liverman CT, Schultz AM, Strawbridge LM. Epilepsy across the spectrum: promoting health and understanding. 1st ed. Washington (DC): The National Academies Press; 2012.

Englot DJ, Ouyang D, Garcia PA, Barbaro NM, Chang EF. Epilepsy surgery trends in the United States, 1990-2008. *Neurology*. 2012 Apr 17;78(16):1200-6. [PubMed](#)

Fountain NB, Van Ness PC, Swain-Eng R, Tonn S, Bever CT Jr, American Academy of Neurology Epilepsy Measure Development Panel and the American. Quality improvement in neurology: AAN epilepsy quality measures: Report of the Quality Measurement and Reporting Subcommittee of the American Academy of Neurology. *Neurology*. 2011 Jan 4;76(1):94-9. [PubMed](#)

Kobau R, Luo YH, Zack MM, et al. Epilepsy in adults and access to care--United States, 2010. *MMWR Morb Mortal Wkly Rep*. 2012 Nov 16;61(45):909-13. [PubMed](#)

Kobau R, Zahran H, Thurman DJ, Zack MM, Henry TR, Schachter SC, Price PH, Centers for Disease Control and Prevention (CDC). Epilepsy surveillance among adults--19 States, Behavioral Risk Factor Surveillance System, 2005. *Morb Mortal Wkly Rep Surveill Summ*. 2008 Aug 8;57(6):1-20. [PubMed](#)

Wicks P, Fountain NB. Patient assessment of physician performance of epilepsy quality-of-care measures. *Neurol Clin Pract*. 2012 Dec;2(4):335-42. [PubMed](#)

Extent of Measure Testing

The new epilepsy measures are being made available without any prior testing. The American Academy of Neurology encourages testing of this measurement set for feasibility and reliability by organizations or individuals positioned to do so.

Evidence for Extent of Measure Testing

State of Use of the Measure

State of Use

Current routine use

Current Use

not defined yet

Application of the Measure in its Current Use

Measurement Setting

Ambulatory/Office-based Care

Hospital Outpatient

Transition

Type of Care Coordination

Coordination between providers and patient/caregiver

Professionals Involved in Delivery of Health Services

not defined yet

Least Aggregated Level of Services Delivery Addressed

Individual Clinicians or Public Health Professionals

Statement of Acceptable Minimum Sample Size

Does not apply to this measure

Target Population Age

Unspecified

Target Population Gender

Either male or female

National Strategy for Quality Improvement in Health Care

National Quality Strategy Aim

Better Care

National Quality Strategy Priority

Effective Communication and Care Coordination

Making Care Safer

Person- and Family-centered Care

Prevention and Treatment of Leading Causes of Mortality

Institute of Medicine (IOM) National Health Care Quality Report Categories

IOM Care Need

Living with Illness

IOM Domain

Effectiveness

Patient-centeredness

Safety

Data Collection for the Measure

Case Finding Period

Unspecified

Denominator Sampling Frame

Patients associated with provider

Denominator (Index) Event or Characteristic

Clinical Condition

Denominator Time Window

not defined yet

Denominator Inclusions/Exclusions

Inclusions

All patients with a diagnosis of epilepsy

Note: Refer to the original measure documentation for International Classification of Diseases, Ninth Revision (ICD-9), International Classification of Diseases, Tenth Revision (ICD-10), and Current Procedural Terminology (CPT) Evaluation and Management (E/M) service codes.

Exclusions

Unspecified

Exceptions

Caregiver is unavailable for a patient who is non-communicative or has an intellectual disability.

Exclusions/Exceptions

not defined yet

Numerator Inclusions/Exclusions

Inclusions

Patients or their caregivers were provided personalized epilepsy safety issue* and education and resources** at least once a year

**Safety issues* to be addressed should be appropriate to the patient's age, seizure type(s) and frequency, occupation, and leisure activities. (e.g., injury prevention, falls, burns, appropriate driving restrictions [including state specific restrictions], or bathing).

***Epilepsy education* topics to be addressed should be appropriate to the patient's age, seizure type(s) and frequency (e.g., diagnosis and treatment options, medication and side effects, treatment specific surveillance laboratory testing, seizure types, triggers and seizure control, management and self-care, psychological issues, social security benefits and social services, insurance issues, education and healthcare at school, employment and independent living for adults, importance of disclosing epilepsy at work, sudden death in epilepsy [SUDEP], status epilepticus, maintaining a healthy life style, driving education, leisure and social issues [including recreational drugs, alcohol, sexual activity and dysfunction, and sleep deprivation], family planning, pregnancy and parenting concerns, and available resources including voluntary organizations and patient support associations).

Exclusions

Unspecified

Numerator Search Strategy

Fixed time period or point in time

Data Source

Administrative clinical data

Electronic health/medical record

Type of Health State

Does not apply to this measure

Instruments Used and/or Associated with the Measure

Unspecified

Computation of the Measure

Measure Specifies Disaggregation

Does not apply to this measure

Scoring

Rate/Proportion

Interpretation of Score

Desired value is a higher score

Allowance for Patient or Population Factors

not defined yet

Standard of Comparison

not defined yet

Identifying Information

Original Title

Measure #4: personalized epilepsy safety issue and education provided.

Measure Collection Name

Epilepsy Quality Measurement Set

Submitter

American Academy of Neurology - Medical Specialty Society

Developer

American Academy of Neurology - Medical Specialty Society

Funding Source(s)

American Academy of Neurology

Composition of the Group that Developed the Measure

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American Board of Internal Medicine: Sharon M. Hibay, RN, DNP

American Clinical Neurophysiology Society: Susan T. Herman, MD

American College of Emergency Physicians: J. Stephen Huff, MD

American Epilepsy Society: Gabriel U. Martz, MD

American Society of Neuroradiology/American College of Radiology: Marvin Nelson, MD

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Financial Disclosures/Other Potential Conflicts of Interest

Unspecified

Endorser

American Epilepsy Society - Medical Specialty Society

Child Neurology Society - Medical Specialty Society

Epilepsy Foundation - Medical Specialty Society

Date of Endorsement

American Epilepsy Society: 2013 Jul 29
Child Neurology Society: 2014 Jul 29
Epilepsy Foundation: 2014 Aug 7

Adaptation

This measure was not adapted from another source.

Date of Most Current Version in NQMC

2014 Jan

Measure Maintenance

Unspecified

Date of Next Anticipated Revision

Unspecified

Measure Status

This is the current release of the measure.

This measure updates previous versions:

American Academy of Neurology (AAN). Epilepsy physician performance measurement set. St. Paul (MN): American Academy of Neurology (AAN); 2009 Aug 10. 50 p.
Fountain NB, Van Ness PC, Swain-Eng R, Tonn S, Bever CT Jr, American Academy of Neurology Epilepsy Measure Development Panel and the American. Quality improvement in neurology: AAN epilepsy quality measures: Report of the Quality Measurement and Reporting Subcommittee of the American Academy of Neurology. Neurology. 2011 Jan 4;76(1):94-9.

Measure Availability

Source available from the [American Academy of Neurology \(AAN\) Web site](#) .

For more information, contact AAN at 201 Chicago Avenue, Minneapolis, MN 55415; Phone: 800-879-1960; Fax: 612-454-2746; Web site: [www.aan.com](#) .

NQMC Status

This NQMC summary was completed by ECRI Institute on December 16, 2011. The information was verified by the measure developer on January 30, 2012.

This NQMC summary was updated by ECRI Institute on January 6, 2016. The information was not verified by the measure developer.

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Production

Source(s)

American Academy of Neurology. Epilepsy update: quality measurement set. St. Paul (MN): American Academy of Neurology (AAN); 2014. 83 p.

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